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CCG Clinical Leaders  
cc'd: CCG Accountable Officers  
NHS KERNOW CCG  
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Dear Colleagues,

I am writing to update you on the latest dementia diagnosis rate figures which were published by the Health and Social Care Information Centre (HSCIC) on 2<sup>nd</sup> October. The data provides the position at the end of August 2015 and shows that of the national estimated number of people, 66.1% have a dementia diagnosis. It is pleasing to see that the momentum has continued over the past 6 months despite not having the data available to you.

### **Diagnosis Rates in your area**

Analysis of the newly released data indicates that your CCG's actual dementia diagnosis rate is 44.6% and your estimated prevalence for people over 65 with dementia is 8344. There is an estimated gap of 4624 people (including under 65s) who may benefit from access to support by way of a dementia diagnosis, and a gap of 1843 to achieve the national ambition. Your efforts to date are greatly appreciated, but there is still some way to go to meet the national ambition of two-thirds diagnosis of the estimated population of people with dementia in your area. I encourage you to make use of the support tools identified below and also to seek assistance from the Intensive Support Team.

Further analysis and benchmarking of NHS KERNOW CCG with others in your area can be found in Annex A. Your 2015-16 CCG plan indicated that you intended to deliver a dementia diagnosis rate of 66.8% by end-March 2016. Within Annex B, we have shown practices within your CCG area; please share this information with all practices allowing them to see how they are performing in relation to their colleagues. As you know, the reason for concentrating on the diagnosis rate is to facilitate the provision of post diagnostic support to people with dementia and their carers which can be put in place following a timely diagnosis. Consequently the work to improve the care of people with dementia and their carers should continue for everyone.

### **HSCIC Data Extract**

As you'll know from previous correspondence, the collection of monthly dementia diagnosis QOF data is subject to a direction, and therefore mandatory. However, there are some practices that have yet to complete their CQRS applications on time and are therefore showing zero returns. Please ensure that all practices in your area are signed into the CQRS system.

The next monthly publication of dementia diagnosis rates for end-September data will be published on the 16th October and will be published monthly until the end of the year. The 'back-data' from April to July will be published on the following dates:

- July data will be published on the 23<sup>rd</sup> October,
- June on the 30<sup>th</sup> October,
- May on the 6<sup>th</sup> November,
- and April on the 20<sup>th</sup> November.
- 2014/15 Year End data is expected to be published by HSCIC in November.

### **Support Tools**

I would like you to continue to work with your practices to encourage them to continue to embed good clinical practice into the timely diagnosis of people with dementia; in particular utilise the range of support tools identified in Annex C. I intend to continue to add to these throughout the year, and my blog <https://www.england.nhs.uk/publications/blogs/alistair-burns/> will also provide updates on future developments.

### **Intensive Support Team**

NHS England is developing an intensive support team as a resource for CCGs to assist them in meeting the national dementia diagnosis ambition. The team will have a wide skill set: clinical, financial, analytical and policy support will all be available on

a tailored case-by-case basis. CCGs can request this resource from NHS England by sending a request to [england.domainteam@nhs.net](mailto:england.domainteam@nhs.net). However, NHS England in conjunction with Regional Directors of Commissioning Operations may call upon the team to assist you, if your diagnosis rates do not increase in the coming months.






## Developing Post Diagnostic Care Support and Meaningful Care

As you know, concentrating on diagnosis has been important in order to facilitate the provision of post diagnostic support. We are now achieving reasonable levels of diagnosis nationally and this year we have moved our focus to improving the care of people with dementia and their carers. Enhancing care planning and post diagnostic support is a priority and reflected in the CQUIN and directed enhanced service.

NHS England's new phase of work is to implement the NHS England Dementia Pathway Transformation Framework based on the Organisation for Economic Co-operation and Development (OECD) dementia pathway. Metrics will be used to collate data on the framework priorities so that resources are focused effectively to ensure the success of delivering the framework.

The framework has 5 elements:

### NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

PREVENTING WELL	DIAGNOSING WELL	LIVING WELL	SUPPORTED WELL	DYING WELL
 Risk of people developing dementia is minimised	 Timely diagnosis, integrated care plan, and review within first year	 People with dementia can live normally in safe and accepting communities	 Access to safe high quality health & social care for people with dementia and carers	 People living with dementia die with dignity in the place of their choosing
"I was given information about reducing my personal risk of getting dementia"	"I was diagnosed in a timely way" "I am able to make decisions and know what to do to help myself and who else can help"	"Those around me and looking after me are supported" "I feel included as part of society"	"I am treated with dignity & respect" "I get treatment and support, which are best for my dementia and my life"	"I am confident my end of life wishes will be respected" "I can expect a good death"
<b>STANDARDS:</b> Prevention <sup>(1)</sup> Risk Reduction <sup>(5)</sup>	<b>STANDARDS:</b> Diagnosis <sup>(1)(5)</sup> Memory Assessment <sup>(1)(2)</sup> Concerns Discussed <sup>(3)</sup> Investigation <sup>(4)</sup> Provide Information <sup>(4)</sup> Care Plan <sup>(2)</sup>	<b>STANDARDS:</b> Integrated Services <sup>(1)(3)(5)</sup> Supporting Carers <sup>(2)(4)(5)</sup> Carers Respite <sup>(2)</sup> Co-ordinated Care <sup>(1)(5)</sup> Promote independence <sup>(1)(4)</sup> Relationships <sup>(3)</sup> Leisure <sup>(3)</sup> Safe Communities <sup>(3)(5)</sup>	<b>STANDARDS:</b> Choice <sup>(2)(3)(4)</sup> BPSD <sup>(6)(2)</sup> Liaison <sup>(2)</sup> Advocates <sup>(3)</sup> Housing <sup>(3)</sup> Hospital Treatments <sup>(4)</sup> Technology <sup>(5)</sup> Health & Social Services <sup>(5)</sup>	<b>STANDARDS:</b> Palliative care and pain <sup>(1)(2)</sup> End of Life <sup>(4)</sup> Preferred Place of Death <sup>(5)</sup>
<b>COMMISSIONING GUIDANCE:</b>				
<ul style="list-style-type: none"> <li>Develop commissioning guidance based on NICE guidelines, standards and evidence-based best-practice.</li> <li>Agree minimum standard service specifications, set business plans, mandate and resources.</li> <li>Work with ADASS, PHE &amp; other ALBs on co-commissioning strategies to provide an integrated service.</li> </ul>				
<b>MEASUREMENT:</b>				
<ul style="list-style-type: none"> <li>Develop Quality, Access and Prevention metrics to form the basis of the CCG scorecard.</li> <li>Identify data sources and agree with HSCIC, et al on the extraction processes.</li> <li>Set 'profiled' ambitions for each metric, to form the basis of the transformation plan.</li> </ul>				
<b>TRANSFORMATION, RESEARCH, INNOVATION, TECHNOLOGY, PATIENT ENGAGEMENT AND BEST-PRACTICE:</b>				
<ul style="list-style-type: none"> <li>Transformation: using CCG scorecard to set &amp; achieve a national standard for Dementia services.</li> <li>Intervention: Intensive Support Team to provide 'deep-dive' support and assistance for CCGs that fall short.</li> <li>Innovation: Intel from Research, Patient involvement, best-practice and technology to influence change.</li> </ul>				
<small>References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.</small>				

In collaboration with various partners, including the Royal Colleges, ADASS, HSCIC, DH, PHE, HEE and Alzheimer's Society, we are in the process of developing quality assurance and outcome metrics to measure service effectiveness. We are also aware that not all support is within the gift of the health service and we are encouraging your social care and local government commissioners to deliver integrated service provision.

### **Survey of dementia support services**

To better understand the provision of dementia support services across England, the Department of Health (DH) have commissioned Age UK to undertake exploratory work to scope out current provision. The survey is now live ([www.ipsos-mori.com/Dementia-Advisers-Survey](http://www.ipsos-mori.com/Dementia-Advisers-Survey)) and is intended to be completed by those responsible for leading the commissioning of dementia services in your area – this may be personnel in a CCG or a Local Authority. A link to the survey will also be emailed so please look out for further communication from Age UK and pass it to the relevant person to complete. The project is supported by NHS England and approval from both the HSCIC and the ADASS Executive Council has been given to undertake the voluntary data collection. All responses will be anonymised and only regional level data will be published, therefore to get a complete picture of provision in your area we would welcome your support to complete this short survey.

### **Dementia Friendly Hospitals**

I have previously written to you and all NHS trusts to ask them to consider how they may facilitate the requests of some carers of people with dementia to continue their caring role in hospital; as championed by campaigns such as “John’s Campaign”. The request is for the carers of people with dementia who are in hospital, to be allowed the option to stay with that person outside of normal visiting hours or even overnight. We are cognisant that this is a practice which hospitals have adopted widely since the early 1990s for the parents of children staying in hospital. We are mindful that some carers of people with dementia are asking to be afforded the same consideration as parents who have children in hospital. We feel that taking into account the wishes of carers and people with dementia is a step in the right direction of encouraging all hospitals to become dementia friendly, and we are looking to develop the national CQUIN for dementia and delirium to take this into consideration.

### **No evidence that Alzheimer's can be transmitted through surgery**

You will all be aware of the recent study published in the medical journal Nature and the subsequent media coverage it has provoked. The study speculated that it might be possible to transmit Alzheimer's disease during certain surgical procedures. I encourage you to reassure all of your patients that there is no evidence that Alzheimer's can be transmitted through surgery, that the NHS has extremely stringent procedures in place to minimise infection risk from surgical equipment, and

patients are very well protected.

The study looked at the brains of eight people who had died of Creutzfeldt-Jakob disease (CJD) during the 1970s following treatment with brain-derived human growth hormone (HGH). HGH is used to treat short stature and, before the risks of CJD were fully known, was derived from the brain tissue of deceased donors, some of whom had CJD. The research team found that in four out of the eight brains studied there were also signs associated with Alzheimer's disease. As these people were outside the age range associated with such signs, the researchers speculate that Alzheimer's might also have been transmitted by the same route as the CJD.

They theorise that it could be possible for Alzheimer's disease to be transmitted by instruments used in brain surgery that are contaminated with infected brain material. This was a small study and this is not evidence that Alzheimer's disease can be transmitted during neurosurgery or any other form of treatment. There is no suggestion that Alzheimer's disease is contagious.

NHS procedures have improved significantly since the 1970s when these patients contracted CJD. Modern surgical equipment used in the UK is very safe and the NHS has extremely stringent procedures to make sure of this. Chief Medical Officer Professor Dame Sally Davies said: *"There is no evidence that Alzheimer's disease can be transmitted in humans, nor is there any evidence that Alzheimer's disease can be transmitted through any medical procedure. This was a small study on only eight samples. We monitor research closely and there is a large research programme in place to help us understand and respond to the challenges of Alzheimer's. I can reassure people that the NHS has extremely stringent procedures in place to minimise infection risk from surgical equipment, and patients are very well protected."*

Dr Doug Brown, director of research at Alzheimer's Society, said: *"There are too many unknowns in this small, observational study of eight brains to draw any conclusions about whether Alzheimer's disease can be transmitted this way."*

Please direct anybody with concerns to the following information:  
<http://www.nhs.uk/news/2015/09September/Pages/No-evidence-that-Alzheimers-can-be-transmitted-through-surgery.aspx>.

### **The Lancet Neurology Report on Dementia incidence**

NHS England welcomes the findings from the recent Policy View published in The Lancet Neurology journal, which showed non-significant changes in overall dementia occurrence over the past 20 to 30 years. The UK CFASII study and the results from the studies done in Zaragoza, Stockholm, and Rotterdam showed that the age-specific incidence of dementia is falling in these regions. The suggested decrease in

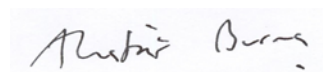
dementia occurrence coincides with improvements in protective factors (such as education and living conditions) for dementia and a general reduction in risk factors (such as vascular diseases) over recent decades. Although the decrease in dementia occurrence is a positive sign, dementia care will remain a crucial challenge for many years as the population ages; it still remains an NHS England priority.

## **Solanezumab**

It is pleasing to see some research breakthrough in the fight against dementia, and in particular Solanezumab is showing promise in that it may slow down brain decline for patients with early stage Alzheimer's disease. A new trial on the drug will report in the autumn of 2016 which should provide definitive evidence as to the effectiveness of the drug. Solanezumab has a different mode of action to all other comparator drugs on the market so we are hopeful for the future and will be following this drug's development closely.

It just leaves me to personally thank you again for the tremendous contribution you have made towards making a positive impact on people with dementia, their families and carers. I will write to you again in October with the next set of extract data. In the meantime, if you would like any general or clinical advice with your work on dementia, or want to discuss anything further, please contact me at [england.domainteam@nhs.net](mailto:england.domainteam@nhs.net). I would be happy to meet you and your colleagues in person, or through a teleconference if more convenient, to discuss dementia matters further if that would be of assistance.

Yours Sincerely



Alistair Burns  
National Clinical Director for Dementia and Older People's Mental Health  
NHS England

## **Annex A - Data Breakdown by CCG**

**Area team: South West**

<b>CCG Name</b>	<b>Diagnosis Rate E.A.S.1 CFAS II (aged 65+)</b>	<b>Diagnosis Rate Delphi 2007 (all ages) March 2015</b>	<b>Dementia Diagnoses (aged 65+) August 2015</b>	<b>Dementia Diagnoses (all ages) August 2015</b>	<b>Dementia Diagnoses (all ages) March 2015</b>
NHS BRISTOL CCG	68.7%	62.7%	2808	2893	2814
NHS KERNOW CCG	44.6%	56.5%	3720	3831	5061
NHS NORTH SOMERSET CCG	66.0%	57.7%	2149	2198	2014
NHS NORTHERN, EASTERN AND WESTERN DEVON CCG	57.9%	55.8%	7592	7762	7888
NHS SOMERSET CCG	61.2%	58.1%	5176	5305	5284
NHS SOUTH DEVON AND TORBAY CCG	60.1%	61.7%	2932	2999	3257
NHS SOUTH GLOUCESTERSHIRE CCG	58.9%	53.0%	1855	1899	1795

## Annex B - Information by practice for this CCG

### Clinical Commissioning Group: NHS KERNOW CCG

Practice Name	Dementia Diagnoses (aged 65+) August 2015	Dementia Diagnoses (all ages) August 2015	Dementia Diagnoses (all ages) March 2015	Change in diagnoses (All ages) March to August
ALVERTON PRACTICE	-	Not Available	98	N/A
BODRIGGY HEALTH CENTRE	56	59	119	-60
BOTTREAUX SURGERY	22	22	41	-19
BRANNEL SURGERY	16	21	16	5
CAPE CORNWALL SURGERY	35	35	39	-4
CARDREW HEALTH CENTRE	4	4	1	3
CARNEWATER PRACTICE	76	82	86	-4
CARNON DOWNS SURGERY	57	59	56	3
CHACEWATER HEALTH CENTRE	31	31	51	-20
CLAYS PRACTICE	38	44	63	-19
CLINTON ROAD SURGERY	18	18	39	-21
FALMOUTH HEALTH CENTRE	81	82	80	2
FOWEY RIVER PRACTICE	48	50	90	-40
HARRIS MEMORIAL SURGERY	38	38	45	-7
HELSTON MEDICAL CENTRE	-	Not Available	96	N/A
HEMPCROFT SURGERY	54	56	61	-5
LANDER MEDICAL PRACTICE	128	132	128	4
LAUNCESTON MEDICAL	183	196	204	-8



CENTRE				
LOSTWITHIEL SURGERY	26	27	71	-44
MANOR SURGERY	105	108	108	0
MARAZION SURGERY	36	37	60	-23
MEDICAL CENTRE CAMELFORD (DR GARROD)	11	11	21	-10
MEDICAL CENTRE CAMELFORD (DR NASH)	22	23	22	1
MENEAGE STREET SURGERY	23	24	40	-16
MEVAGISSEY SURGERY	21	21	66	-45
MORRAB SURGERY	-	Not Available	47	N/A
MULLION HEALTH CENTRE	75	76	83	-7
NARROWCLIFF SURGERY	106	106	109	-3
NEETSIDE SURGERY	14	15	36	-21
NEWQUAY HEALTH CENTRE	100	102	117	-15
OAK TREE SURGERY	54	54	88	-34
OLD BRIDGE SURGERY	52	53	125	-72
PENALVERNE SURGERY	37	38	44	-6
PENRYN SURGERY	108	114	115	-1
PENSILVA HEALTH CENTRE	-	Not Available	58	N/A
PERRANPORTH SURGERY	75	76	77	-1
PETROC GROUP PRACTICE	-	Not Available	92	N/A
PHOENIX SURGERY	41	43	47	-4
POOL HEALTH CENTRE	71	73	71	2
PORT ISAAC SURGERY	50	50	89	-39
PORT VIEW SURGERY	59	60	62	-2

PRAZE-AN-BEEBLE SURGERY	27	29	49	-20
PROBUS SURGERY	29	30	67	-37
QUAY LANE SURGERY	21	22	42	-20
RAME GROUP PRACTICE	67	71	118	-47
ROSEDEAN SURGERY	97	98	92	6
ROSELAND SURGERIES	52	52	47	5
ROSMELLYN SURGERY	37	39	79	-40
SALTASH HEALTH CENTRE	104	110	115	-5
ST BLAZEY SURGERY	39	40	74	-34
ST KEVERNE HEALTH CENTRE	13	14	34	-20
ST MARY'S HEALTH CENTRE	5	5	18	-13
ST.AGNES SURGERY	42	43	68	-25
STENNACK SURGERY	76	77	140	-63
STILLMOOR HOUSE	51	55	130	-75
STRATTON MEDICAL CENTRE	105	107	98	9
SUNNYSIDE SURGERY	28	29	52	-23
TAMAR VALLEY HEALTH	125	128	139	-11
THREE SPIRES MEDICAL PRACTICE	119	123	136	-13
TRESCOBÉAS SURGERY	-	Not Available	95	N/A
TREVITHICK SURGERY	36	36	29	7
VEOR SURGERY	78	83	85	-2
WADEBRIDGE & CAMEL ESTUARY PRACTICE	47	48	106	-58
WESTOVER SURGERY	65	66	66	0

## Annex C

### **Key actions that practices can routinely undertake to increase dementia diagnosis rates**

- **Use the Dementia Quality Toolkit (DQT):** Maintaining excellent data quality can only be maintained by regular cleansing. The DQT consists of a series of reports and queries run directly on GP systems to identify patients who may have dementia, but who are not coded as such within the practice. The DQT can be downloaded from the North of England Commissioning Support Unit (NECS) website: <http://www.necsu.nhs.uk/dementia>.
- **Secondary Care Data:** Develop standard working practices of information sharing between primary and secondary care, particularly around diagnosis.
- **Other searches:** This involves reviewing lists of people:
  - Who have **EVER** been prescribed cholinesterase inhibitors (donepezil, galantamine, rivastigmine), or memantine.
  - 65 years and over **AND ALL** those in Care homes who have been prescribed antipsychotic medication.
  - Previously coded with local dementia codes, that is codes that are not part of the QOF Dementia Indicator Set.
  - Coded with conditions suggestive of dementia.
  - Resident in Care / Nursing homes. This review includes review of patient notes especially letters where text may refer to the possibility or diagnosis of dementia.
- **Seek support from your Clinical Network:** specific clinical advice and support is available through a network of clinicians with an interest in Dementia. Working closely with Regional Team, the Clinical Network colleagues will provide targeted support, tools and resources to aid better understanding and improvements in local dementia diagnosis rates and post diagnostic care and support. Please contact [england.domainteam@nhs.net](mailto:england.domainteam@nhs.net) if you wish you be put into contact with one of the network contacts.
- **Additional Alzheimer's Society Support:** The Alzheimer's Society continues to provide additional support in some CCGs areas which includes public awareness activities, supporting diagnosis in care homes and improving post-diagnostic support with more Dementia Advisers. For further information on this additional support please contact [england.domainteam@nhs.net](mailto:england.domainteam@nhs.net) or George McNamara at [george.mcnamara@alzheimers.org.uk](mailto:george.mcnamara@alzheimers.org.uk).